

C. Le Saux¹, D. Jackson-Perry², I. Gilles¹, C. Storari¹, O. Keserue Pittet¹, E. Cart¹, O. Nawej Tshikung³, M. Cavassini², K.E.A. Darling²

¹ Center for Primary Care and Public Health, Unisanté, Lausanne; ² Service of Infectious Diseases, Lausanne University Hospital, Lausanne; ³ Division of Infectious Diseases, Geneva University Hospitals, Geneva

Background and aim

- Thanks to medical advances in the treatment of HIV, people living with HIV (PLWH) on antiretroviral therapy have a life expectancy approaching that of the general population.
- Despite this, living with HIV remains challenging due in part to HIV-related stigma, which has a negative impact on mental health, quality of life¹, and access to treatment for PLWH².
- Between March 2020 and January 2021, a cross-sectional survey study using a validated 12-item HIV stigma scale was completed by 5,563 PLWH enrolled in the Swiss HIV Cohort Study (SHCS). HIV stigma was present across all demographic groups and disclosure concerns were reported in >80% of participants. However, being quantitative, that study could not provide a deep understanding of stigma experience or coping strategies.
- The aim of the current qualitative study is to explore the way PLWH perceive and experience HIV stigma in their lives, including when accessing healthcare in Switzerland. Here, we present the first stage of analysis.

Methods

- Patient and Public Involvement (PPI) was an integral part of this study, a collaboration between qualitative researchers, clinicians, and a patient expert.
- Between 1st March and 31st May 2022, PLWH were invited to take part in an observational study using qualitative methods.
- Inclusion criteria: adults (>18 years old) living with HIV; enrolled in the SHCS; treated at the Infectious Diseases Outpatients Service of Lausanne University Hospital; French speaking.
- Exclusion criteria: active mental health issues including depression; on anti-psychotic or anti-depressant treatment; diagnosed neurocognitive impairment.
- Consenting participants attended confidential one-to-one semi-structured interviews of up to 90 minutes with trained researchers.
- Interviews were recorded and then transcribed.
- In this first stage, analyses were conducted using IRaMuTeQ. This software performs various text analyses, including discourse classification based on word frequency and co-occurrence.
- The classification generated by the software was then interpreted by members of the research team trained in qualitative methods.

Results

- 19 PLWH treated at the centre for infectious diseases in Lausanne
- 11 were women, 12 were from European countries, 13 stopped studies before high school, 16 had been diagnosed for more than 10 years, and 10 had a CD4 nadir score < 200 cell/ml.
- Mean age was 49 years.
- Analyses showed that two main themes emerged from PLWHs' discourse:
 - Social representations of HIV** (Fig. 1a) → overrepresented among: men, participants from European countries and participants with higher levels of education
 - Medical experience of HIV** (Fig. 1b) → overrepresented among: women, participants from non-European countries and participants with lower levels of education
- Each of these two categories was subdivided into five themes (see Figure 2).

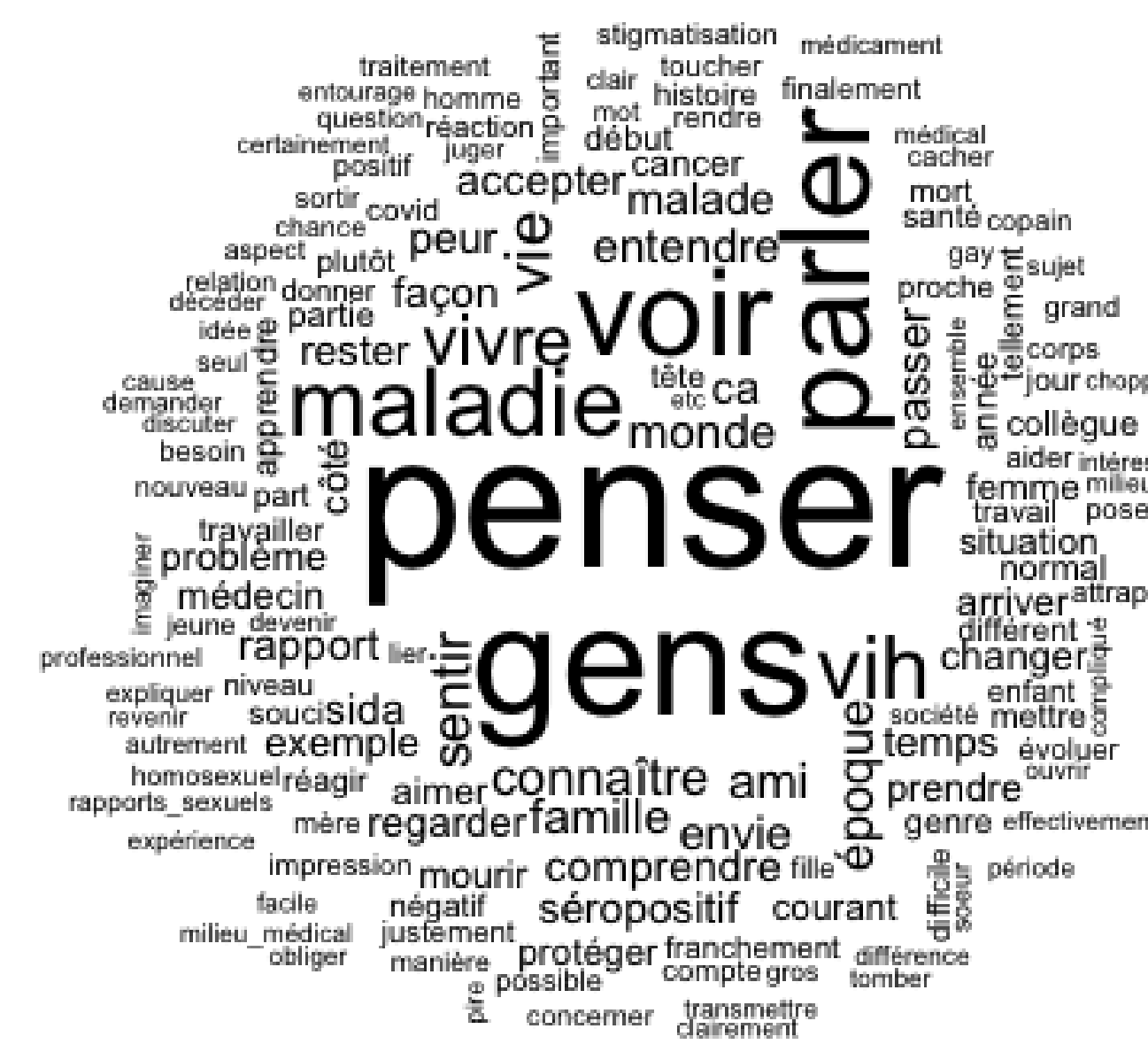


Figure 1a: Terms most used in 'social representations' themes



Figure 1b: Terms most used in 'medical experience' themes

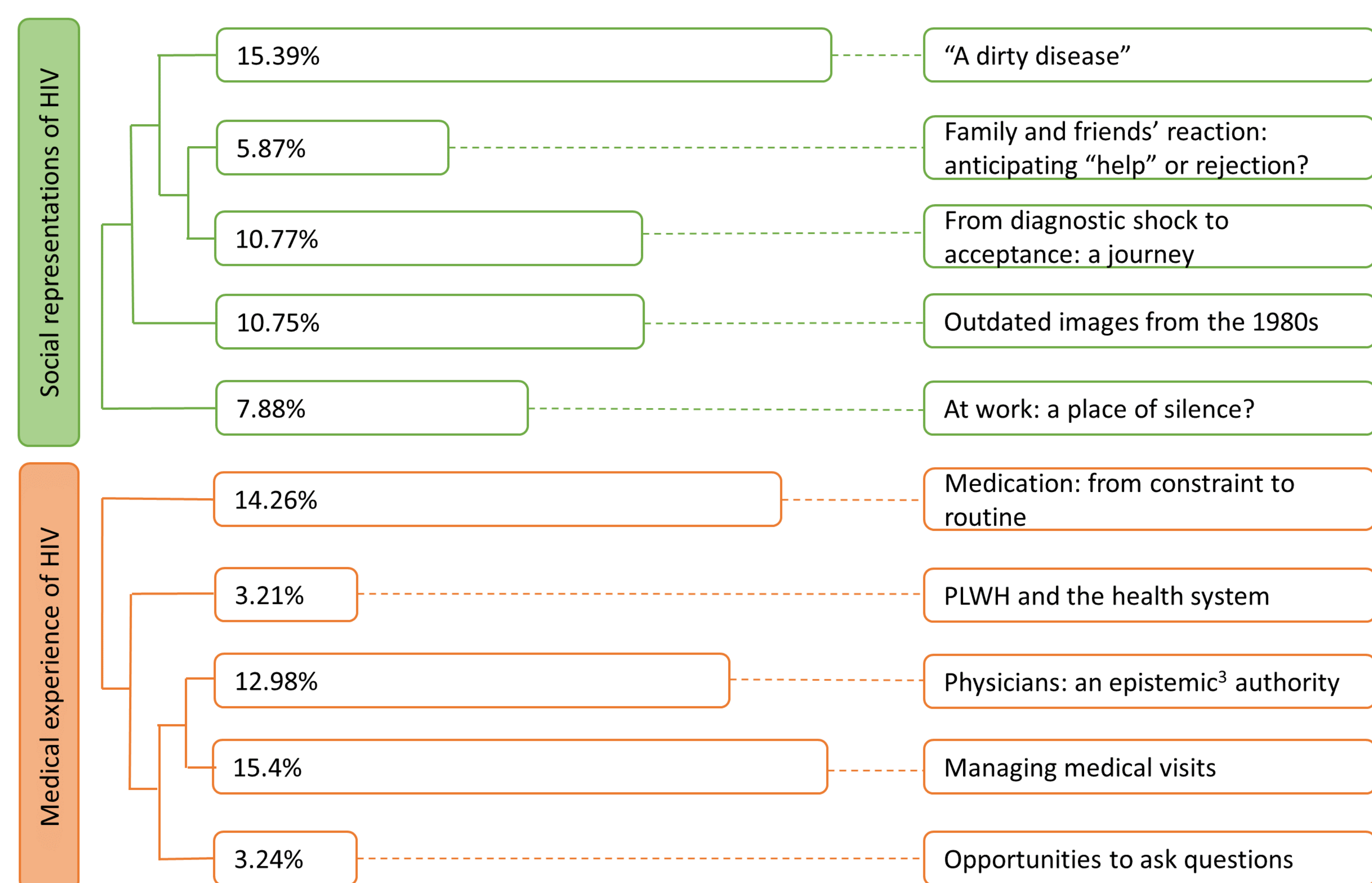


Figure 2: Dendrogram of the different themes discussed by participants

In general, participants...

- perceived living with HIV as being taboo. Even if they expressed a need to speak about their HIV status, they often chose not to, or only to a close circle of "reliable" people
- reported little or no experience of enacted stigma but all have developed strategies to avoid being stigmatised. Perceived risks of stigma included rejection or being associated with HIV prototypical⁴ groups (e.g., "whores", "junkies", "homos")
- felt that discussing their HIV status was part of a personal journey: from early strategies of hiding "it", and carefully selecting people with whom it could be discussed, to self-acceptancy
- felt that social perceptions of HIV from the 1980s persist; To help to change this, visibility and increased media presence of individuals living with HIV is essential but participants are aware this could make them vulnerable to stigma

In healthcare, participants...

- reported few experiences of enacted stigma or of a negative impact in accessing healthcare
- had the premise that healthcare professionals would be competent enough not to stigmatise
- sometimes did report stigmatising encounters with healthcare professionals. In these situations, they tended to reinterpret or minimise that behaviour
- considered healthcare professionals to be epistemic³ authorities. They have the knowledge and are trusted; they also have considerable influence on the decision of patients regarding whether to discuss their HIV status, when, and with whom

Discussion and implications

- Few participants had experienced enacted stigma: in most cases this may have been because they used strategies to avoid it; in other cases it was because they did not have negative reactions when discussing their status. Either way, anticipation and avoidance play a large role in daily life and organization and indeed carry more weight than experiences of enacted stigma. This paradox echoes findings in recent research which shows that while 85% of respondents think that PLWH deserve the same level of support and respect as people with any other long term health condition (indicating low stigma), 83% also think that PLWH often face negative judgement from others in society⁵.
- Visibility of PLWH and increased knowledge, for example through media discussion of HIV, could have a positive impact on public perceptions of HIV and therefore be a strategy to reduce stigma. This is supported by recent research in the field⁵.
- Acceptance of living with HIV is perceived as a personal journey: it is necessary to detach oneself from the perceived and anticipated judgement of others. In this sense, people who have accepted living with HIV tend to see treatment as something automatic rather than a constraint; they have decided who to tell and are comfortable with this.
- Healthcare professionals and more particularly physicians hold epistemic authority: they have the medical knowledge, they are trusted, and they play a central role in the way PLWH perceive and avoid HIV stigma. There is a potential paradox here: in their concern to protect patients, physicians may perpetuate the notion that HIV must be kept secret, from the waiting room to the home. Contradicting the notion that keeping HIV secret is protective, participants in this study described how being able to discuss their HIV status could be beneficial⁶.
- This study had limitations. The study exclusion criteria precluded access to PLWH whose discourse and experience might differ from what is presented here. Consequently, it is not possible to say whether our observations are applicable to the PLWH who were not presented in this study.
- Key message : Navigating anticipated stigma constitutes a considerable burden for PLWH, despite limited experiences of enacted stigma. Wider public discussion of HIV, particularly concerning advances in treatment and modes of transmission, could attenuate this. Healthcare professionals, often seen as an all-knowing authority, sometimes advise patients not to discuss their HIV status. Despite the good intentions behind this advice, it may be damaging rather than 'protective' and requires nuance: some PLWH find that talking about their HIV is beneficial and even empowering.

Acknowledgements

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- Epistemic: relating to knowledge or to the degree of its validation.
- Prototypical: is used to indicate that someone or something is a very typical example of a type of person or thing (Collins English Dictionary)
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